Summer/Fall 2018

# KHF Hemosphere

## Snapshot: Program Year
## July 1, 2017 – June 30, 2018

It is encouraging and reassuring that we ended the year in the black again spending 64 cents of every dollar on program services. This was achieved primarily due to the Walk revenue. Many people came together to walk toward a better future for their children and grandchildren and to raise money for that purpose. All the money our walkers raised stayed right here in Kentucky.

We had a great camp, which – at a cost of $40,000 – is our most expensive undertaking but also the most rewarding. We held our fifth successful Advocacy Day in Frankfort in partnership with NORD (National Organization for Rare Diseases) and the Tri-State Bleeding Disorders Foundation, educating legislators about bleeding disorders and the needs and concerns of the bleeding disorders community. Our family support events, such as the Family Day at the Zoo and the Holiday Event, are as popular as ever, and continue to grow.

We were able to assist more families in need with emergency assistance thanks to a grant from the Hemophilia Alliance Foundation. Families are typically referred by the Treatment Centers in Lexington and Louisville. We offered a multitude of educational opportunities and support services, ranging from educational dinners, scholarships, newsletters, to medic alert emblems, helmets, and other child safety items.

Programs and services included a wonderful summer camp experience for 32 children, teens, and their siblings. We Provided 7,500 copies of our Hemosphere newsletter to Kentucky's bleeding disorders community, healthcare professionals, and donors. We reached and engaged with 850 people through our educational and support activities. We offered 17 educational sessions in Louisville and Lexington on a variety of pertinent topics. These smaller events allow for Q & A and for families to get to know and interact with each other. We responded to 49 requests for emergency assistance helping 33 families. We provided 61 medic alert emblems and helmets. We provided 11 scholarships and sponsorships and added 46 new families to our database for a total of 1,002 families. And little things matter too, 558 adults and children received birthday greetings.

There is never a fee for our programs and services. We continue to be cautiously optimistic about our future finances, but we also realize that we will have to continue working hard to raise the money we need for a reliable funding base that allows us to serve you! This is especially true in light of some funding decreases from the pharmaceutical sector. Our plans this year are to grow the Walk, expand our advocacy efforts, and focus on building our Teen Leadership Program.

This year we commemorated our 58th service anniversary. Every year, we thank the founders of KHF for starting this organization out of concern for others and to exchange support. We want to continue in that tradition for years to come. We thank our Board of Directors for guiding us and all of our volunteers and supporters for helping us achieve our mission in good times and in lean times!

# **Special** News

## San Diego HTC Looks at Cardiovascular Disease in Young People with Hemophilia

As individuals with hemophilia live longer and reach life expectancy rates comparable to the general population, their healthcare providers will continue to encounter clinical challenges inherent in treating and managing aging patients, including cardiovascular disease (CVD). There are several established risk factors associated with CVD such as hypertension, overweight, obesity and an abnormal lipid profile. With this knowledge in hand and with an eye towards prevention, investigators at the Rady Children's Hospital San Diego (RCHSD) Hemophilia and Thrombosis Treatment Center (HTC) decided to look at CVD risk factors in some of their younger hemophilia patients.

The lead author of the study was RCHSD medical director Courtney Thornburg, MD, MS. She and her research team approached patients during their comprehensive care visits, ultimately recruiting 43 males with hemophilia A or B between the ages of 5 and 20 (average age 12). Patient data and additional information was culled from a combination of electronic health records for clinical data, standardized measurements of weight, height, waist circumference and blood pressure and screenings of glucose and lipids. Patients and/or their caregivers also completed questionnaires relevant to medical history, lifestyle and family history (FH).

The results showed high rates of overweight and obesity among the participants. Investigators also observed other CVD risk factors, including (pre)hypertension in 28% and "borderline" high lipids in 19% of the subjects. Higher levels of physical activity correlated with normal weight levels, while higher weights were linked to greater factor consumption. Seven participants (16%) reported a FH of CVD. These and additional findings prompted the authors to hypothesize that cardiovascular risk factors could be identified and measured as part of a comprehensive clinic visit and that best practices to mitigate those risks could be integrated by the entire HTC team.

"HTCs may utilize internal resources, including dieticians, physical therapy (PT) and child life specialists to recommend therapeutic lifestyle changes for a healthy diet plus avoidance of tobacco and alcohol use. In addition, if children are identified with overweight or obesity at a comprehensive clinic visit they may be referred to the primary care physician for follow-up and/or to obesity and behavioral health programs as appropriate. PTs may perform targeted joint and muscle examinations and provide patient-specific recommendations to increase conditioning and sports participation."

The authors cited study limitations. The data was based on one HTC visit instead of over time, which is important for longer term monitoring of factors such as body mass index (BMI), blood pressure, lipid profiles. While physical activity, smoking and nutrition data were collected only by self-reporting without validated questionnaires, future studies could be augmented using food logs to measure caloric intake and accelerometers to measure physical activity. Lastly, future studies would also benefit from the inclusion of a healthy control group. The authors note that by addressing certain limitations, future studies could be more effective in CVD risk reduction, especially in concert with the primary care physician (PCP).

"Ultimately, resources will be required to monitor the impact of interventions on BMI, cholesterol, hypertension and physical activity. Further study is warranted to determine if HTCs can partner with PCPs and appropriate specialists to promote cardiovascular health and risk reduction. Interventions should include shared decision-making strategies to set realistic goals and methods of self-monitoring" concluded the authors.

This study "Risk Factors for Cardiovascular Disease in Children and Young Adults with Haemophilia," was published in the June 2018 issue of *Haemophilia*.

# Learning About Hemophilia: Through the Heart and Head

*Helene Zereik*

I closed my eyes for just a moment, and when I opened them again, my baby was five years old and starting kindergarten.

G, born in 2007, is my firstborn and has severe hemophilia B. I left my job in human resources when he was a baby, because it was getting hard to explain all my absences due to his constant hospital visits and injuries. My mother had a home daycare, and I would sometimes leave him there. I never put him in a private daycare, and we never did any extracurricular activities besides swimming when he was a toddler.

I sheltered him, and I sheltered myself. Then school started, and I could no longer shelter him. Short of homeschooling him, there was nothing I could do besides send him to a public school.

I wondered how I could send him to school and not feel anxious, nervous, stressed. I searched for the right school within our district. I decided on a smaller school with fewer than 300 kids. I felt that it was important for all the teachers, administration, and lunch monitors to know who my son was.

I felt better knowing that everyone would identify my son not only by his first name and his heaps of curls, but also because he had a bleeding disorder.

I wondered, how can I prepare him? How can I educate him about his disorder? G was old enough to know that he had something that most kids did not have or had never heard of, that he was different somehow. He knew that he could get “boo-boos” more than other kids. Yet he was still too young to understand that he couldn’t pretend to be Batman or Spider-Man and attempt to climb walls. He could not comprehend the dangers of simple things like playing on the monkey bars or climbing the ladders at gym.

I sat him down to tell him that Mommy was going to have a meeting with the district nurse, the hospital nurse, and the school staff to talk about how to deal with his getting hurt sometimes. I showed him his medical kit that I had prepared. It contained popsicles for lip and tongue bleeds. It had superhero band-aids for his scrapes, a Lightning McQueen ice pack, and colorful bandages. I supplied his teacher with children’s books on hemophilia. The teachers read short stories such as All About Me and the Bob Goes to School series given to me by the Canadian Hemophilia Society. G seemed happy with the items but was still a little anxious.

**“I don’t like hemophilia. I don’t like myself. I don’t like my body,” he would repeat, he would cry.**

My heart ached as he spoke those words. As the year progressed, they became weekly sayings.

I simply said, “This is your body and this is how it works.” I told G that in order for him to participate in the fun at school, he had to take his special medication that would make him strong. It gave him super-power abilities to be able to play at gym and just be like all the other kids. I told him that he was a regular little boy, but that he just needed an extra special touch to be able to jump around and play.

# **Event** News


## 2018 Fall Semester Scholarship Award

KHF awarded two $500 post-secondary education scholarships for the 2017 fall semester. John Rhea received the Herb Schlaughenhoupt, Jr. Memorial Scholarship. John, the son of Clark and Sally Rhea of Louisville, is a graduate student at the University of Kentucky pursuing a Master's degree in Health Administration. He maintains a 3.5 GPS and plans to graduate in May of 2019. John feels called to work in the field of hematology. His dream is to run a Hemophilia Treatment Center.

Samantha Johnson received the Terry D. Turner Memorial Scholarship. Sam is the daughter of April and Mark Zimmerman of Evansville. Sam is starting her freshman year at Bellarmine University this fall semester. Her major is nursing, and her desired goal is to become a nurse practitioner. Sam enjoys helping people and has volunteered in her local community throughout high school. She has received several awards for her efforts including Shire's coveted Teen Impact Award in 2017. Sam has been attending KHF's summer camp for children and teens with bleeding disorders since she was a little girl and will now move into a Youth Counselor Role.

## New KHF Officers and Directors for 2018-2019

Officers elected by the membership present during the business portion of the Summer Family Event-Annual Meeting are Venus Marcum, Louisville, President; Cory Meadows, Louisville, Vice President; Kristin Taylor, Louisville, Treasurer; and Laura Webb, Louisville, Secretary. The officers' term is one year, which can be renewed for a second year. We congratulate them for their willingness to serve in this important volunteer capacity.

New directors, who were elected for three-year renewable terms are Patricia Ashby, ARNP, MSN, BS, retired Nurse Practitioner who worked for fifteen years at the Adult Louisville Hemophilia Treatment Center; Patrick Dunegan, Customer Service Representative at Charter Spectrum, NORD Ambassador, and GSSI Executive Director; Christi Hille, Homemaker & Caregiver for two young boys; and Travis Price, Supervisor at Amerisource Bergen and valued KHF Camp Volunteer. All are residents of Louisville. Congratulations to all new and current directors for their dedicated volunteer service.

## Summer Family Event – Annual Meeting

The Summer Family Event's winning combination of activities were valuable education and information, Walk Kick-Off, and a fun cruise on the Ohio River. At the beautiful Hyatt Regency Louisville Hotel, our guests enjoyed visiting with our exhibitors and listening and engaging in productive discourse with our presenters. Speaker topics provided something for everyone by addressing "The Science of Hemophilia: A Changing Landscape," "Resilience: Growing through Life's Changes," "504 Plans and IEPs," and "Parenting with a Chronic Condition." Children's activities were aptly facilitated by Connie Thacker of Christian Fellowship. The Walk Kick-Off Luncheon stirred up much enthusiasm for the 2018 Unite for Bleeding Disorders Walk, and the steamboat cruise on the Ohio River provided a chance for Saturday afternoon sightseeing and relaxation. The following companies exhibited at the event: Accredo, Aptevo, Bayer HealthCare, Bioverativ, Cottrill's Pharmacy, CSL Behring, CVS Caremark, First Choice Home Infusion, Genentech, HEMA Biologics, Pfizer, and Shire. We appreciate their participation and support.

# Event News


## Summer Camp

KHF's Camp Discovery for Children and Teens with Bleeding Disorders and their Siblings had another great season this year. Twenty-five children and teens participated in this year's KHF summer camp program. The five-day program was jam-packed with outdoor fun and adventure as well as educational and empowerment activities. The overriding goals for every camper are to have fun, make friends, and learn to self-infuse at camp. We make a concerted effort, plan, and tailor our activities for camp to meet this challenge put forth by our campers. Swimming and capturing the flag remain all-time favorite activities. A special treat this year for our campers and young adults was the "Leading Edge" empowerment program facilitated by Patrick Torrey from acclaimed GutMonkey and sponsored by Pfizer. The canteen program operated by teen campers for a second consecutive year housed many sought after goodies. Here campers could redeem their virtual dollars which they earned for exemplary behavior, attitude and achievements for snacks, toys, and other desirable items.

Again this year, unanimously, all campers proudly donated a portion of their "dollars" to help sponsor a child in India through the Save One Life Program. During our final night event, Camp Director, Justin Lindhorst, provided us with an update on nine-year-old Genesis. Genesis who has hemophilia lives in a small village in India with his parents and siblings and loves soccer. In addition to the sponsorship, KHF will send Genesis a soccer ball with greetings from our campers. Our thanks and appreciation go to our Camp Director, Justin Lindhorst; the Infirmary Team, Donna Haffler, RN and Rania Salem, RN; and all our outstanding counselors and camp committee members who planned, implemented, and ensured another superb and safe summer camp program. Our gratitude also extends to our sponsors who made camp possible. They are Bayer HealthCare, Bioverativ, CSL Behring, CVS Caremark, Grifols, HEMA Biologics, Kosair Charities, Novo Nordisk, Pfizer, Shire, WHAS Crusade for Children.

## Walk Wrap Around Events

Walk Wrap Around Events are key to boosting the fundraising efforts of every Walk Team. These are fun activities that the entire team can participate in. They include car washes, bake sales, cook offs, yard sales, and much more. Last year's winning Walk Team, Mac's Pack from Lawrenceburg, held a Golf Scramble for family and friends. Team Captain, Alane Foley, who is also little Mac's mom, reports: "We had our first annual 'Mac's Pack Putt with a Purpose' Golf Scramble on July 7th at Lakeview Springs Golf Course in Frankfort. Twenty-four golfers participated in a two player best ball format. Mulligans were available for purchase as well as Split the Pot chances. Lunch was graciously donated by Penn Station in Frankfort. The winners were Haley Case and Colby Martin. Mac's Pack Putt with a Purpose raised $665 for their Walk Team, "Team Mac's Pack."

Last year's 3rd place winner, Team LEVI from Cynthiana, organized a Motorcycle Run for their family and friends. Team Captain, Karen Lucky, who is LEVI's grandmother, reports: "There were 45 bikes on the road for LEVI on August 25th. It was such a beautiful day and such an impressive sight to see our friends and bike community come out and support LEVI's cause. The annual Cynthiana Rod Run was taking place on the same day. So, both groups joined for a parade through downtown Cynthiana. It was a sight I was grateful to witness and see captured with photos. Always riding for a cause is these bikers' motto. The Motorcycle Run raised over $1,000 for their Walk Team, "Team LEVI."

# **More** News

## 2017 – 2018 KHF Fund Drive
## We appreciate your support!

**Challenge Gift, $25,000**
Forcht Bancorp, Mr. & Mrs. Terry Forcht

**Fundraisers Toward Meeting the Challenge, $13,000+**
Various Corporate Solicitations and Fundraisers

**Forcht Society/Challenge Donors, $1,000 +**
Mrs. Marion Forcht
Chevron Matching Employee Funds
The Community Foundation of Louisville, for the Zoeller Company
Dynacraft Company Employees
David Hasch
Don L. Mattingly

**Donors, $500 +**
Kroger Community Rewards
Joseph H. Cieslak, Louisville Oral Surgery & Dental Implants

**Donors, $250 +**
Anonymous
Community Health Charities
J.B. & Elaine Hitt
in honor of Glen, Sr. & Deborah Hitt
Glen, Sr. & Deborah Hitt
Harrell Locksmith
Jennifer Hitt
Bill Stopher

**Donors, $100 +**
Clark County REMC
Greg Fiscus
Mike Gatton
in honor of John & Greg Gatton
Kylie Hall
Rickey James
Vivian Marcum
Chris Saul
Mike & Jenifer Schultz

**Donors, Up to $99**
Amazon Smiles
Crystal & Rodney Fouch
Susan Geralds
Louise Hardaway
Stan Hankins
Sharen & Stanley Harmon
Eric Hayes
Brett Herald
Mike Koziak
Louisville Web Group
Terry Moore
Christina Romano
Rania Salem
Lonnie & Linda Surratt
Woman of Immanuel, Immanuel UCC

# Learning About Hemophilia: Through the Heart and Head

continued from page 3

G was too young for me to explain clotting or severe bleeds. So I made a visual for him. I opened the faucet to let water drip slowly. I explained that the water was like his blood. When he got hurt, his body was like the faucet, and he needed to make it stop running. The only way to do that was to take his medication. And this explanation seemed to work. As G got older, I used kitchen ingredients, adding flour to water to show how a substance can thicken a liquid. He seemed satisfied with those visuals.

I kept it simple. There is so much emotion when your child starts school, and it wouldn't have done G any good to have more information than necessary. When he started school, I gave him a little necklace with a heart on it. I told him that it was my heart he was taking to school, and that when he felt nervous, he could take it from his bag and hold it for a minute. This reassured both of us.

The important thing for kids with hemophilia to learn as they grow is that they need to tell someone when they get hurt. There's a fine line when determining a serious injury. Does it require Mom to come and assess, or getting out of class? That fine line is a slow and long learning process for the child and the parent. In the beginning, I would run to the school daily. G would get a paper cut, and the teacher would be nervous and call me. I tended to go as often as possible to lessen the stress for the staff. I instructed staff to call me anytime he fell, hit himself, cut himself, or was in any pain. This was simpler, and though it was stressful for me, it reassured G to see me and to hear me tell him he was okay.

I also joined the PTA, and I volunteer regularly, attending all the school outings. It makes G feel safe and takes a load of stress off the staff. This helped, but it still has not made him understand that he has to be extra careful.

I told him that he needed to always tell me if he felt pain anywhere in his body. I spent much time talking, repeating, showing him books, explaining things to him. Kids live in the moment, and my job was to repeat myself over and over, hoping that as he got older, he would be less likely to throw himself from the top of the monkey bars, and that he would think twice about pulling dangerous stunts. With each passing year, G has slowly started to understand that he is a little different from other kids. I'm hoping he is realizing that although he has different needs, he can still do most everything.

So how can you explain hemophilia to your children? You do it simply, in small words, and regularly. You talk to them. You continuously ask them questions and let them be part of the conversation. Does my son understand everything? No. Does he listen to everything I say? Definitely no! But I'm hoping that with each passing year, he will learn to love his body, own his disorder, and know that it does not define who he is as a person. I'm hoping he'll understand that he has options and opportunities just like everyone else, and that the sky's the limit for him.

Helene Zereik has three children and lives in Canada. She spends her days stepping on Lego pieces and running to the school to assess her son's injuries. Before she had children, she used to do her nails and hair regularly. She worked in human resources, where she would engage with other professionals, who never sounded like a cartoon or Darth Vader. Sometimes, she misses those days.

# Do The Five

*Follow these steps to prevent or reduce complications of bleeding disorders*

1. **Get an annual comprehensive checkup at a hemophilia treatment center.**
2. **Get vaccinated – Hepatitis A and B are preventable.**
3. **Treat bleeds early and adequately.**
4. **Exercise to protect your joints.**
5. **Get tested regularly for blood-borne infections.**

To find out more about the National Prevention Program developed by the National Hemophilia Foundation in collaboration with the Centers for Disease Control and Prevention (CDC), click on www.hemophilia.org or call toll-free 800-42-HANDI.

KHF does not give medical advice or engage in the practice of medicine. KHF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

# UpComing Events

**Poinsettia Sale - November/December, Statewide, Fundraiser**

**Year-End Community Event - December 2, Louisville, Family Support Event**

**Vegasville Gala - February 23, Louisville, Fundraiser**

**Kentucky Advocacy Day - February 28, Frankfort, Peer Advocacy Event**

KOSAIR CHARITIES

COMMUNITY HEALTH CHARITIES™ KENTUCKY

WHAS CRUSADE FOR CHILDREN

KENTUCKY HEMOPHILIA FOUNDATION
1850 Taylor Avenue #2
Louisville, KY 40213-1594

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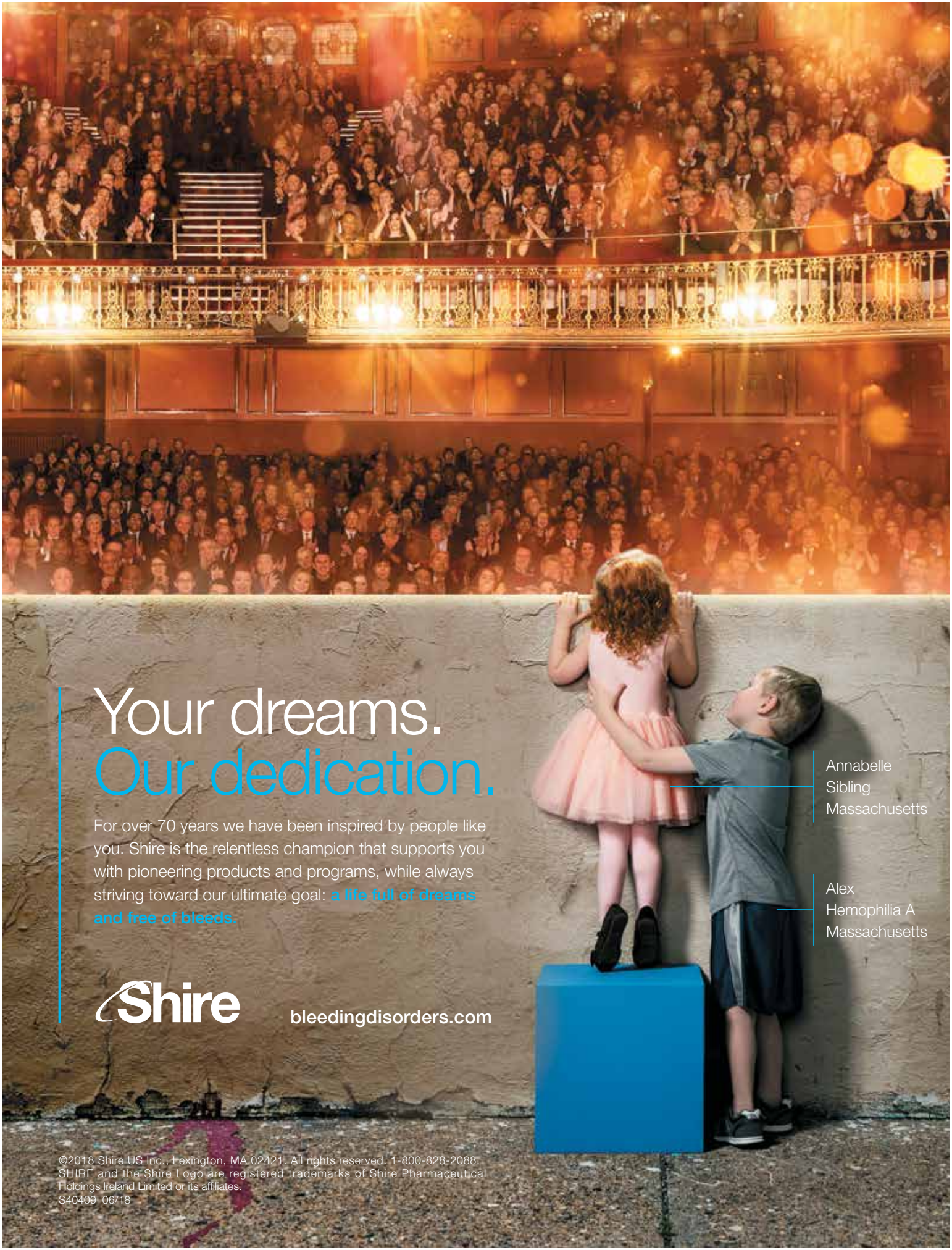

**A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS**

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

## WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

## WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

**HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

## HOW SHOULD I USE HEMLIBRA?

**See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

## WHAT ARE THE OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

**The most common side effects of HEMLIBRA include:** redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

## Medication Guide Brief Summary
## HEMLIBRA® (hem-lee-bruh)
## (emicizumab-kxwh)
## injection, for subcutaneous use

### WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

**HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

### WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

- Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.
- HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

### BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

### HOW SHOULD I USE HEMLIBRA?

**See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

### WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

**The most common side effects of HEMLIBRA include:**
- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

### HOW SHOULD I STORE HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than 7 days at 86°F (30°C) or below.
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

### GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

### WHAT ARE THE INGREDIENTS IN HEMLIBRA?

**Active ingredient:** emicizumab

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 11/2017

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use | 150 mg/mL



Genentech
*A Member of the Roche Group*

Pfizer Hemophilia

# DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.

PATIENT AFFAIRS LIAISONS

## Working for you—From the home of Motown to the Bluegrass State

**Name:** Chris Liddell

**Home state:** Michigan

**Fun fact:** If I'm watching TV, it's most likely sports-related. Go Tigers!

**Ideal vacation spot:** Anywhere quiet, unplugged from all electronics

**What past experiences can you bring to this job?** I've worked in hemophilia for over 10 years, so I've collaborated with and advocated for different members of this community.

**To get in touch with Chris, call**
**Pfizer Hemophilia Connect 1.844.989.HEMO(4366)**

### What we do:

- Provide helpful information about Pfizer Hemophilia programs and services
- Serve as a resource to hemophilia treatment centers to help patients obtain access to Pfizer medicines
- Serve as a primary point-of-contact for local advocacy groups
- Participate in local and national events and programs
- Upon request, meet with patients and caregivers to answer questions related to Pfizer Hemophilia resources

"IT'S IMPORTANT TO CONNECT ON ALL LEVELS: HTCs, PATIENTS, FAMILIES, THE WHOLE COMMUNITY."

—Chris Liddell

# UNLOCKING YOUR SELF-POTENTIAL

## ONLY ADVATE® HAS 15 YEARS OF EXPERIENCE IN THE REAL WORLD AS A RECOMBINANT FACTOR VIII[1]

- Proven in a pivotal clinical trial to reduce the number of bleeding episodes in children and adults when used prophylactically[2]*
- Third-generation full-length molecule, similar to the factor VIII that occurs naturally in the body[1,2]

*Multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20-40 IU/kg every 48 hours, or pharmacokinetic-driven, 20-80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis.[2]

**The market leader in hemophilia A treatment**
(Based on 2016 data published July 2017)[3]

**Learn more at ADVATE.com**

## ADVATE Important Information

### What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

## DETAILED IMPORTANT RISK INFORMATION

### Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

### What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

### What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

### What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

### What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

**You are encouraged to report negative side effects of prescription drugs to the FDA.**
**Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.**

**For additional safety information, please see Important Facts about ADVATE on the following page and discuss with your HCP.**

**For Full Prescribing Information, visit www.ADVATE.com.**

**References: 1.** Grillberger L, Kreil TR, Nasr S, Reiter M. Emerging trends in plasma-free manufacturing of recombinant protein therapeutics expressed in mammalian cells. *Biotechnol J.* 2009;4(2):186-201. **2.** ADVATE Prescribing Information. **3.** The Marketing Research Bureau, Inc. The plasma proteins market in the United States. 2016.


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ADVATE
[Antihemophilic Factor (Recombinant)]

ADVATE
[Antihemophilic Factor (Recombinant)]

# Important facts about

**ADVATE [Antihemophilic Factor (Recombinant)]**

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

### What is the most important information I need to know about ADVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you.

### What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

### Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

### How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

### What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

### What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

| | | |
|---|---|---|
| cough | headache | joint swelling/aching |
| sore throat | fever | itching |
| unusual taste | dizziness | hematoma |
| abdominal pain | hot flashes | swelling of legs |
| diarrhea | chills | runny nose/congestion |
| nausea/vomiting | sweating | rash |

Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

### What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE with other people, even if they have the same symptoms that you have.

**The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA approved product labeling can be found at www.ADVATE.com or 1-888-4-ADVATE.**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.**



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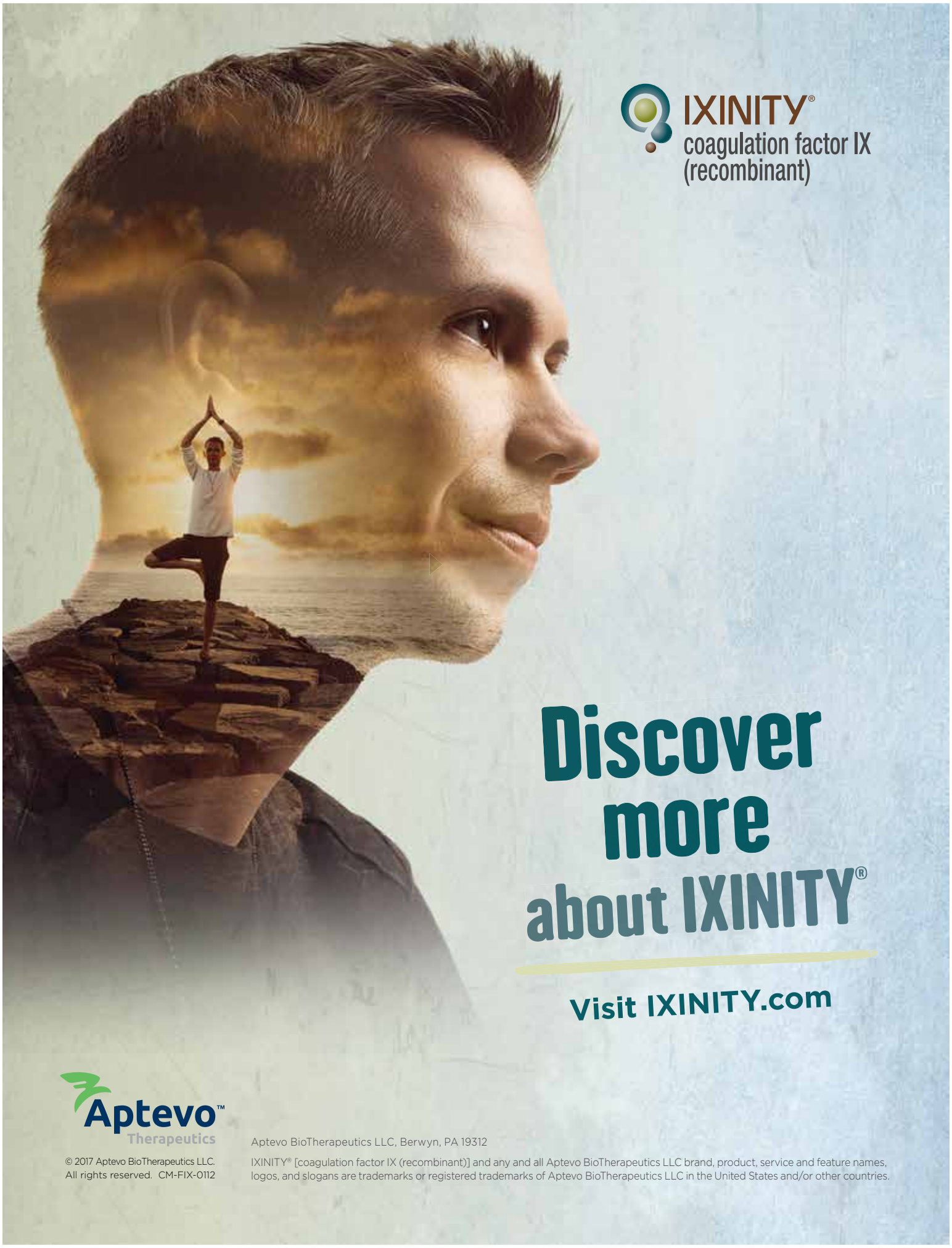




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